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ABSTRACT

A research project examined the current roles of learning disability nurses within multi-professional and multi-agency teams in a range of care settings in the United Kingdom (UK). It also studied the effectiveness of current educational provision for this branch of nursing, in terms of current roles and activities, and the perceived needs of users and carers. Methodology included a mail survey of a random sample of 10% (1,864) of nurses in the learning disability parts of the UKCC Professional Register, of which 756 (41.9%) responded; case studies of nurses in practice; focus groups of people with disabilities and their carers; a survey of 163 courses' documentation; and a detailed study of a sample of 12 courses. Findings identified major changes in the roles of learning disability nurses from the provision of care and support within hospital settings to a diversity of roles and activities providing support for users in a variety of settings. These roles included the direct provision of care and support in residential settings, provision of specialist advice, and management of a variety of services. Educational providers were committed to the development of appropriate nurse competence with particular emphasis on the development of care, management, research, information, and personal skills. However, not only did provision vary, but both practitioners and employers identified deficiencies in educational preparation in terms of clinical skills, health care, communication, and management and leadership skills. (Author/YLB)

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Research Highlights 47

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research HIGHLIGHTS

Educational Preparation for Learning Disability Nursing: Outcomes Evaluation of the Contribution of Learning Disability Nurses within the Multi-professional, Multi-agency Team

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Abstract

This research project was designed to examine the current roles of learning disability nurses within multi-professional and multi-agency teams in a range of care settings. It also examined the effectiveness of current educational provision for this branch of nursing, in terms of current roles and activities, and the perceived needs of users and carers.

The research team identified major changes in the roles of learning disability nurses from the provision of care and support within hospital settings to a diversity of roles and activities providing support for users in a variety of settings. These roles included the direct provision of care and support in residential settings, the provision of specialist advice and the management of a variety of services.

The research team found that educational providers were committed to the development of appropriate nurse competence with particular emphasis on the development of care, management, research, information and personal skills. However, not only did provision vary, but both practitioners and employers identified deficiencies in educational preparation in terms of clinical skills, health care, communication and management and leadership skills.

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Main Findings

1. The changing role of learning disability nurses

Many of the participants in our survey had worked through the major recent changes in policy and practice. over 30% had trained and qualified before 1980 and less than 25% had qualified in the 1990s. These nurses accepted that there has been a major reconceptualisation and restructuring of their field of practice in recent years. These included changes in:

- *terminology and values* The respondents in our survey recognised that a change in terminology underpinned a major shift in values and systems of care. The emphasis had shifted to take account of what service users wanted - people with learning disabilities had more choice, more rights, more dignity and more privacy;
- *policy* Respondents linked changes in terminology and values to changes in government policy, especially the shift from custodial care within institutions to more personalised care in the community;
- *roles* Most respondents acknowledged that the changes in policy and location of care had entailed a major impact on the nature of learning disability nursing. Nurses identified two contradictory trends: a greater emphasis on the learning disability nurse as a manager and at the same time a greater diversity of roles performed by learning disability nurses providing specialist support for people with learning disabilities and their families.

The majority of nurses who qualified over ten years ago were initially employed in hospitals on traditional hospital nursing grades. Whereas the majority of respondents in our study continued to be employed by the NHS:

- only a minority retained traditional 'hospital' titles (35.6%) and a substantial minority (43.9%) now had social care titles such as home or team leader.

Most were working in community settings providing care and support for people with learning disabilities, mainly living in residential units:

- only a minority (18.6%) worked within hospitals or specialist units. Half worked either in community-based residential units (51.1%) or provided support to people with learning disabilities living in the community. A substantial minority of the respondents (22.7%) were not employed as nurses and nearly a quarter (23.4%) of these respondents did not see themselves as nurses.

Whereas the provision of care and support for users and carers remain a major component of learning disability nurses' work, our respondents reported that management, liaising and education were the most important elements of their work. Their main reported activities were:

- *administration and management* record keeping, report writing (93.5%), attending meetings (81.1%), managing staff and dealing with personnel issues (77.0%);
- *user and carer support* working individually with users (85.4%), assessment of users (78.9%), health surveillance (62.1%), working with informal carers (families/friends) (60.9%), working with groups (52.0%);
- *liaison activities* liaising with the multi-disciplinary team (79.2%), liaising with outside agencies (69.8%);
- *education* developing personal competencies (47.2%), training staff (46.4%), teaching students (25.2%).

Our study of nursing practice in multi-disciplinary teams indicated that nurses and other professional members of the MDT appeared willing and able to acknowledge each other's standing and skill. Four distinctive components of the nurses' role were acknowledged:

- *direct care* Learning disability nurses were acknowledged to have unique knowledge and skills in providing care and support for people with learning disabilities;
- *management and administration* While other professionals acknowledged the contribution that nurses made to management of services, nurses themselves made little reference to the contribution they could make to the management of services;
- *liaison work* Learning disability nurses accepted that other professionals had specialist knowledge about aspects of learning disability but emphasised their overall and integrated knowledge;
- *education: a source of expertise* All multi-disciplinary team members considered that the knowledge and expertise learning disability nurses had developed about people with learning disabilities enabled them to provide advice to other professionals.

Some nurses, especially relatively junior nurses working in residential settings, spend the majority of their time providing direct care:

- *the nurse as care provider* We observed a registered learning disability nurse, on a shift during which she was the most senior nurse and had overall responsibility not just for her sub-unit that provided residential care for 8 individuals with severe learning disabilities but also for the whole residential unit. It is clear from the overall profile of her activity during the shift that the direct care aspect of her work took precedence. Whereas she did spend time on administrative work (97 mins, 28%) and even some educational activity (8 mins, 2%), for most of the shift she was engaged in direct care (241 mins, 70%), providing medication, toileting, bathing and helping residents eat. We identified 61 separate activities. Over half (32, 52%) were related to user care.

This type of role is by no means universal. As nurses progress in their careers so their roles change. They move into managerial or more specialist roles. This change in roles is reflected in changing pattern of activities. The change is clearest for senior nurses in managerial roles:

- *the nurse as manager* We observed one senior registered nurse who was the acting unit manager responsible for a forensic unit. This nurse spent the majority of his time in administration and management (115 mins, 41%) and the least proportion of his time in care activities (40 mins, 14%). The remainder of his time was spent either in liaison work (71 mins,

25%) or education (55 mins, 20%). He spent most of his day in meetings (121 mins, 45%), on the phone (57 mins, 21%) or doing paperwork (57 mins, 34%).

Specialist nurses have a more varied workload. They provide support to users in a variety of settings and travelling between these settings is a major feature of their lives. Whereas specialist nurses provide direct services to users, more often their specialist input is targeted at providing support for families or residential staff.

- *the nurse as specialist* One registered nurse who worked in a multi-disciplinary team specialised in providing support in the community for users with challenging behaviours. While she had limited direct contact with users, she was actively involved in identifying the causes of challenging behaviours and developing strategies for dealing with them. This accounted for nearly half of her work activities (191 mins, 45%). The remainder of her time was equally divided between travelling (76 mins, 18%), liaison work (76 mins, 18%) and management (77 mins, 18%).

2. Users and carers: perceptions of learning disability nurses

Users who participated in our focus groups had contact with and showed awareness of the identity and role of learning disability nurses. They identified a number of components of this role:

- *the medical aspect of nurses' role* Users tended to see the distinctive activities in functional or medical terms such as taking blood pressures or giving medication. The participants referred to people with 'special needs' as being given 'plenty of help' by such nurses citing the help nurses provided with toileting;
- *the nurse as a helper and enabler* Several participants saw the nurse as providing them with help, both routinely and during a crisis;
- *the learning disability nurse as a friend* Whereas many users saw the activities of the learning disability nurse primarily in terms of their functional activities, others emphasised their personal relationship with a specific nurse. They saw their nurse as a friend whom they could trust;
- *distinguishing learning disability nurses from other nurses* Participants differentiated learning disability nurses from other nurses in terms of activities, appearance and location. Learning disability nurses provided general help, they were friendly and provided help in the community. Other nurses provided technical treatments, wore uniforms and worked in hospitals.

Families had similar perceptions to users:

- *recognising the role of the learning disability nurse* It was evident that many, but not all, of the participants who were parents had experience or contact with learning disability nurses. For some this extended to many years of accumulated experience;
- *the nurse as a skilled expert* Participants indicated that in their experience learning disability nurses possessed particular expertise in care of people with learning disabilities whether this was medical, epilepsy and medication, or dealing with challenging behaviour;
- *the nurse's family focus* A number of parents spoke of learning disability nurses as possessing skills in working with parents or families. These ranged from liaison or co-ordinating skills to direct quasi-therapeutic help or support for carers at an emotional level;
- *the nurse's vocation and personal characteristics* While users tended to see these personal characteristics in terms of friendship, family members saw it in terms of a vocation;
- *comparisons with other nurses* One of the perceived advantages of being in contact with a learning disability nurse, compared to other nurses, was that learning disability nurses possessed specialist knowledge in relationship to learning disabilities.

3. The educational preparation of learning disability nurses

Courses aimed to produce competent practitioners who were committed to the interests of people with learning disabilities and had the appropriate knowledge to provide care that enhanced the autonomy of people with learning disabilities. Pre-registration courses aimed to develop a basic all-round competence in learning disability nursing whereas post-registration courses aimed to enhance pre-existing competencies in specific ways. The aims included:

- *ensuring fitness for purpose* All the pre-registration course documentation surveyed included a statement that the aim of the course was to educate a competent nurse who was 'fit for purpose';
- *developing competence in nursing and social work* featured in joint nursing and social work courses;
- *developing reflective practice* Whereas technical skills were important, most courses were committed to developing reflective practice through critical analysis and the appropriate use of evidence;
- *commitment to life-long learning* Course documentation indicated that nurses should acquire the capacity to develop and keep up-to-date;
- *enhancement of skills* Post-registration courses were more specialised and had aims that suited their specific specialist function.

The designers of learning disability educational courses attached great importance to their value and ethical base. There was a strong emphasis, especially in pre-registration and specialist practitioner courses, on the value base of all student learning. Specialist courses tended to be seen primarily in technical terms, and therefore were justified in utilitarian terms, that is the development of knowledge and skills to benefit users.

- *Course documentation* regularly included statements that people with learning disabilities should be afforded the same dignity and respect as other members of society. Within this ethical framework the role of the nurse was conceptualised as promoting the dignity of people with learning disabilities by empowering them and enabling them to make choices.

In specialist courses, the main emphasis was on knowledge underpinning specific skills or which could be used to address a specific need. For other courses, knowledge specification was mainly extensive, rather than intensive.

Both pre-registration and specialist practitioner courses provided detailed specification of the types of knowledge they were designed to provide. A detailed analysis of 11 pre-registration diploma courses identified:

- 165 separate areas of knowledge with 68 underpinning the provision of care and support, 65 specialist areas of knowledge providing insight and understanding of the situation of people with learning disabilities and 32 areas of knowledge linked to the management of care;
- *knowledge related to providing care and support* individual care (34 areas identified), systems of care (14), nursing (14), ethics (6);
- *specialist areas of knowledge* human anatomy and physiology (18), learning disabilities (17), human growth and development (15), health (8), supporting academic disciplines (7);
- *management knowledge* legal and professional issues (15), management processes (10), research and information (7).

The course documentation provided specification of the skills which students were expected to have on successful completion of the course. Detailed analysis of 11 pre-registration diploma courses identified the following skill areas:

- *care skills* care assessment, planning, implementation and evaluation (11 courses), counselling skills (9), lifting and handling (7), observation (7), drug management and administration (6), maternal care (6), management of aggression and conflict (6), managing challenging behaviour (6), family-centred care (6), providing opportunities for work and leisure (6);
- *management skills* working as part of MDT (11), resources management (9), managing/initiating change (8), multi-agency working (8), decision-making skills (7), record keeping (7), risk assessment and management (7), critical thinking/analysis (6), resourcing, purchasing, providing and contracting (6), clinical audit and quality enhancement (6), time management (6), leadership skills (6);
- *research skills* computer skills (10), study skills (9), doing research (9), research/evidence-based practice (7), academic style and referencing (7), presentation skills (7), library skills (7), data collection (6), literature research and review (6), portfolio construction (6);
- *personal skills* communication skills (11), reflection/reflective practice (10), self-awareness (9), self-directed learning (8), interpersonal skills/relationship building (8), teaching, supervising, assessing and mentorship skills (6), life-long learning (6), special communication techniques (6).

4. Evaluations of the learning process

In our survey we asked respondents to evaluate both their own educational preparation and that of current students. Generally respondents were critical both of their own educational preparation and that of current students.

Own preparation Less than 24% of the respondents felt that their education had fully prepared them for their first post and less than 11% felt that it had fully prepared them for their current role. The majority (91%) of respondents identified one or more educational deficits that had become apparent within two years of qualification. The major deficits included:

- *administration and management deficit* leadership/management skills (60.6% of respondents identified it as a deficit), how to deal with stress (38.3%), time management/ organisational skills (22.5%);
- *client care therapy skills* (for example behavioural, cognitive, counselling) (39.5%), working with informal carers (23.6%), practical/clinical skills (17.5%);
- *liaising* liaising with outside agencies (23.9%), liaising with the multi-disciplinary team (20%);
- *education* dealing with students (17.9%).

Whereas respondents acknowledged some limitations in their own education, they felt that innovations such as the development of Project 2000, had not enhanced the quality of education. In particular they felt that students completing such programmes were not adequately prepared for practice. They identified the following limitations of current educational preparation:

- *placement problems* too much theory and not enough practice (26.5% of respondents identified it as a deficit), limitation of current placements (24%), colleges out of touch with current practice (3.2%);
- *skills shortage* management skills (10%), care for specific needs (5%), clinical skills (4.8%), communication skills (3%);
- *inadequate preparation for practice* unable to make student/nurse transition (7.8%), problems with students' attitudes (4.3%);
- *education programme* problem associated with common foundation programme of pre-registration courses (4.1%).

Current students were invited to comment on the ways in which their education was preparing them for practice. Post-registration students were clear that their courses had or would:

- *change their practice* They all agreed that as a direct result of undertaking their courses they were 'more confident' because they now had a knowledge base to support their practice. They spoke of courses giving them a broader 'outlook and knowledge base' which in turn equipped them with the confidence to go back into their practice areas and start making changes.

While pre-registration students accepted that the main aim of their courses were to prepare them for practice, most of the students we interviewed who were nearing the end of their course did not feel adequately prepared to take on the full responsibility of a registered nurse. They identified a number of specific areas in which they did not feel adequately prepared:

- *clinical skills* Students were concerned that their clinical skills were not adequate for practice in areas such as gastrostomy feeding and administration of injections;
- *health needs* Students also considered that they were unprepared for meeting the health needs of people with learning disabilities;

- *communication skills* were identified by a number of students who felt they need more input into this area;
- *management and leadership skills* Students were concerned about their management skills. One group reported that the amount of input they received from school on managerial and leadership skills was minimal and they felt that they were expected to develop these skills within their practice placement areas.

Employers had clear views about students' learning experiences. They identified limitations in terms of:

- *their own involvement in the development of education programmes* Only two of the employers we interviewed felt they had close involvement in the design and development of the curriculum. Most employers did not have the opportunity to influence the design and delivery of the curriculum to ensure it reflected their specific service needs;
- *skills shortages* Only one employer was impressed with the skills of her employee, all the other employers expressed serious concerns about the skill levels of students. They felt that students were not adequately prepared for practice;
- *need for in-house training* All employers recognised the limitations of students' preparation for practice by providing their own in-house preparation. This took the form of specific induction training including mentorship or supervision. In some cases employers appeared to provide what seemed to amount to a 'crash course' in key care skills;
- *theory/practice gap* Whereas employers recognised that courses provided students with opportunities to develop appropriate knowledge and values, they were concerned about the theory/practice gap. They did not view students who successfully complete courses as ready for practice.

The course documents we analysed placed users and carers at the centre of the educational process:

- *users* were the prime focus within documents and a main concern. It was clear that course designers saw their courses as ensuring that future nurses would be aware of and could meet the needs of carers. The course documents indicated that users were involved in course design and in some cases delivery of the programme;
- *families* Whereas users formed the central focus of courses, families were less frequently and less explicitly identified. It appeared that in some courses their interests were not separated from those of service users. The course documents indicated in some cases families were involved in the design and delivery of the programme.

Whereas most courses made general reference to the involvement of users and families in course design and development, only exceptionally did course documentation provide detailed information on the role of users and carers in course delivery.

In interviews course lecturers acknowledged the role of users and families in the design and delivery of curricula but it was clear that they saw this role as limited and secondary:

- *participation in design* Only one lecturer responsible for a pre-registration course spontaneously mentioned the involvement of users and carer representatives in the design of curricula;
- *participation in delivery* The majority of the lecturers involved users or families in the delivery of curricula. Some lecturers felt this involvement was tokenistic.

In our interviews with current nursing students, none of the groups identified any sort of involvement of people with learning disabilities or carers in the classroom context.

- only one group of students referred to users or carers, commenting that while none were involved they 'should be though. It needs to be changed'.

The three focus groups comprising people with learning disabilities readily referred to student nurses whom they encountered within care or service facilities. Involvement tended to be:

- *passive* The self advocacy group appeared to be a focus for education and the day centre itself appeared to provide a placement for nurses. One participant explained their feeling that control of such placements was largely in the hands of those in the educational setting;
- *lack of choice* Service users appeared to have some choice about whether or not they were involved in educational initiatives but not whether their 'services', such as their own homes, were used to provide learning opportunities.

Users showed:

- *awareness* of the importance of nurses learning about them and in their environment and;
- *a willingness* to be involved in professional education, 'I mean we could and it would be nice if we did help like. I think it would be a better idea'.

Among those family members interviewed a number had experience of being involved in professional training and education:

- *involvement in course development* was limited. One group indicated that their input into teaching had developed as the course matured: 'We actually got into doing the curriculum basically and altering it'. For another their involvement was in terms of a course that was 'already set up and running';
- *teaching was ad hoc* One carers' group ran one and a half day workshops for the local social services department and also for social work, psychology and Project 2000 courses at the local higher education institution.

Families were willing to expand involvement and acknowledged the:

- *importance of involvement* Families have been concerned that nurses should be well trained and many were willing to offer their own experiences to validate theoretical teaching;
- *valuing of the expertise* Involvement was a way of confirming that carers have expertise. They saw their knowledge as applicable to a wide variety of relationships and systems rather than being experts solely in respect of one individual family member.

Further information

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Details about the Project

These highlights are based on research commissioned by the English National Board for Nursing, Midwifery and Health Visiting (ENB) from July 1998 until July 2000. The research was designed to:

- analyse the discrete role of the learning disability nurse within the multi-professional and multi-agency team in a range of care settings;
- assess the effectiveness of educational outcomes in professional practice in relationship to the perceived needs of service users and carers and the roles and activities of nurses within multi-professional, multi-agency teams.

In the first part of the study the research team used three linked methods to examine the discrete role of the learning disability nurse:

- *a questionnaire survey* of a 10% random sample of nurses who were on learning disability Parts of the UKCC Professional Register. The questionnaire was distributed to the 1864 nurses in the sample in March 1999. A final total of 756 questionnaires were returned (41.9% of the sample).
- *case studies of nurses in practice* Ten multi-disciplinary teams were selected to represent different types of team and different areas of learning disability nursing practice. Twenty-four nurses were observed in practice. Sixteen of these nurses also completed diaries which provided a more extensive record of their activities.
- *focus groups with people with learning disabilities and their carers* were used to examine perspectives of the role of professionals and the adequacy of educational preparation. A series of eight focus groups were held, three of the groups were composed of people with learning disabilities, one group was made up of seven family members and two people with learning disabilities and the final four groups were composed of family members, mostly parents.

In the second part of the study the research team used two research methods to evaluate the educational preparation of learning disability nurses for their contribution to the multi-professional, multi-agency team:

- *a survey of course documentation* Documentation from a total of 163 courses for learning disability nurses was scrutinized and analysed.
- *a detailed study of a sample of courses* Twelve courses were chosen for more detailed study with interviews with course leaders, students and the main employers (seven agreed to be interviewed). Eight students also completed diaries.

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